

# Virginia's Individuals with Special Health Care Needs

## Oral Health Basic Screening Survey 2019 Results



The Virginia Department of Health (VDH) Dental Health Program has years of experience with oral health surveillance systems and open-mouth basic screening surveys (BSS) for Head Start, third grade children, older adults, and pregnant women. However, there is a gap in statewide data for individuals with special health care needs (ISHCN). This data would be useful to promote oral health efforts specific to this population.

Limited oral health status data, including some open-mouth ISHCN BSS, was found in other states, including Nevada, Rhode Island, Oregon, California, Washington, and Michigan. The Behavioral Risk Factor Surveillance System, which is the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services, includes self-reported data from ISHCN.

### **In 2019, Virginia expanded Oral Health Surveillance System activities with three goals:**

1. Promote, coordinate, and implement Virginia's first statewide ISHCN BSS to capture data regarding the oral health status for ISHCN of all ages.
2. Improve access to dental services for ISHCN by expanding components of the VDH Dental Health Program's oral health initiatives focused on ISHCN.
3. Collaborate and share data widely with partners and other agencies with the power to impact positive changes in access to dental care for this priority population group.

VDH began by gathering representatives from multiple organizations working with ISHCN, including: Virginia Care Connection for Children, Virginia Department of Behavioral Health and Developmental Services (DBHDS) Office of Integrated Health, Special Olympics of Virginia, Virginia Board for People with Disabilities, Virginia Partnership for People with Disabilities, and Parent to Parent of Virginia.

### **The following questions/challenges were among the first addressed within the partner and VDH staff meetings:**

**1. How to define ISHCN for this survey:** *ISHCN have medical, physical, sensory, intellectual, or psychological conditions making it necessary to modify participation in home, work, or social activities. This can include intellectual or developmental disorders, long-term chronic health conditions, and physical limitations. ISHCN often need caregiver or healthcare support, assistance, or special services.*

### **2. How to reach this population effectively:**

- Work with collaborative partners to identify BSS sites/venues
- Challenge VDH and DBHDS remote-supervised dental hygienists to find sites in or near the health districts where they provide existing services

### **3. Ways to improve previously used BSS forms; i.e., additional questions:**

- Work with VDH dental and Care Connection for Children staff
- Gain input from partners to determine useful data points

### **4. Timeline/Start date:**

- Survey target dates: June – August 2019
- Chosen to avoid overlap with third grade BSS

### **5. Target number:**

- At least 30 from each remote dental hygienist's health district
- Designated as a "convenience" sample statewide

### **6. Incentives to encourage participation:**

- Free oral screening with referrals for follow-up care
- Oral health "goody bags" with toothbrush, toothpaste, floss, and educational brochures

### **Resulting BSS Timeline Narrative:**

The project timeline began in December 2018 by reaching out to VDH staff and community partners with expertise on ISHCN, followed by meetings and discussions January-April 2019. During March-May 2019, VDH prepared the survey instrument based on previously used forms and collaborative partner input; VDH Internal Review Board (IRB) approved the survey instrument May 31. In June, all VDH and DBHDS dental hygienists completed calibration for the survey. The launch of the first BSS site, June 7-8, was the Special Olympics of Virginia Summer Games combined with the Healthy Athletes Special Smiles program where 71 athletes participated in the BSS. Based on feedback from examiners, participants, and caregivers, the BSS survey instrument underwent modification and re-approval by the IRB in July. During July-August 2019, VDH epidemiology staff prepared and launched BSS data entry in REDCap. The ISHCN BSS was completed as of August 31, 2019, and data entry and evaluation began.

### **2019 ISHCN BSS Statistics:**

- The final statewide total number of ISHCN screened was **425**.
- Thirteen dental hygienist examiners were actively reporting from thirteen different Virginia health districts.

### **Questions on the BSS Instrument (see Appendix A) and Resulting Data:**

1. Do you have a special health care need, condition, disability, or chronic illness? (See the definition of a disability used for this survey)

**Result:** 99.3% of the 425 participants reported having a special health care condition, disability, or chronic illness. This statistic is indicative of how successful the survey was in reaching the target population.

a) If yes, please indicate the condition here.

**Result:** The majority of respondents, 30.6%, reported intellectual or cognitive disabilities as their special health care condition. Many identified with more than one disability, condition, or disorder. The numbers below include all conditions noted by each respondent. A quarter (25.4%) of the participants reported neurological disorders; 15.2% reported psychological conditions; and 14.2% reported developmental disorders. Also of note, almost 11% of the participants did not report anything specific. (**See Appendix B** chart of the conditions/disorders/syndromes labeled or reported under each response category)

Response	Count	Percentage
Intellectual/Cognitive Disabilities	129	30.6%
Neurological Disorder	107	25.4%
Psychological Conditions	64	15.2%
Developmental Disorders	60	14.2%
Chronic Medical Conditions	49	11.6%
Physical Disabilities	46	10.9%
Genetic Disorder	24	5.7%
Sensory Disabilities	2	0.5%
Suspected Disability/Condition	0	0%
Missing Data	46	10.9%

## 2. Your age in years

**Result:** The lowest participant age was one year. The highest age was 84 years. The average respondent age of the sample population was 32 years.

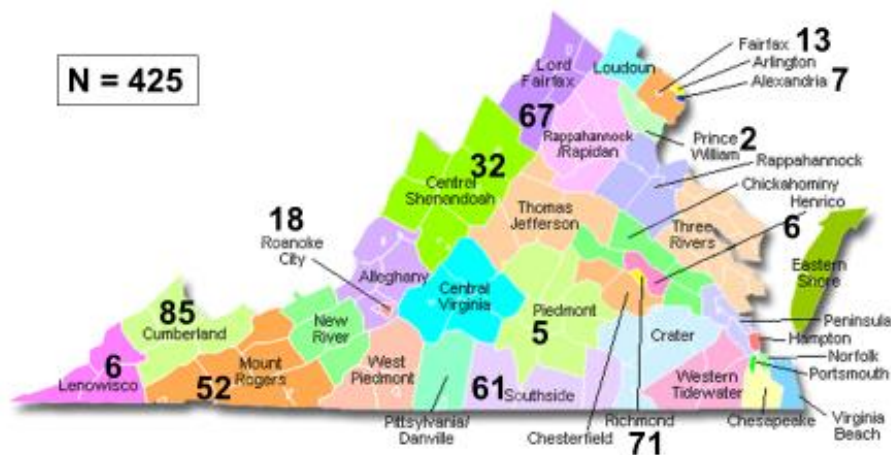
## 3. Your city or county of residence

**Result:** All survey participants resided in Virginia. Buchanan County in Southwest Virginia had the greatest number of respondents, followed by adjacent Russell County. Overall, participants from this survey resided in 157 different cities or counties across Virginia. See the map below showing the number of people surveyed in each health district. Some health districts are a single city while some involve multiple cities and/or counties.



## 2019 ISHCN BSS Demographics

N = 425



Participants represented 157 different Virginia cities and/or counties.

VDH  
Virginia Department of Health  
www.vdh.virginia.gov

### 4. Which of the following best describes your living situation?

**Result:** Most respondents (65.4%) reported living with a parent or guardian; the next most common living situation was living in a group home (17.6%). Only about 5% of individuals reporting living by themselves, which is to be expected since ISHCN with significant conditions often require more care and may not be able to manage daily needs on their own.

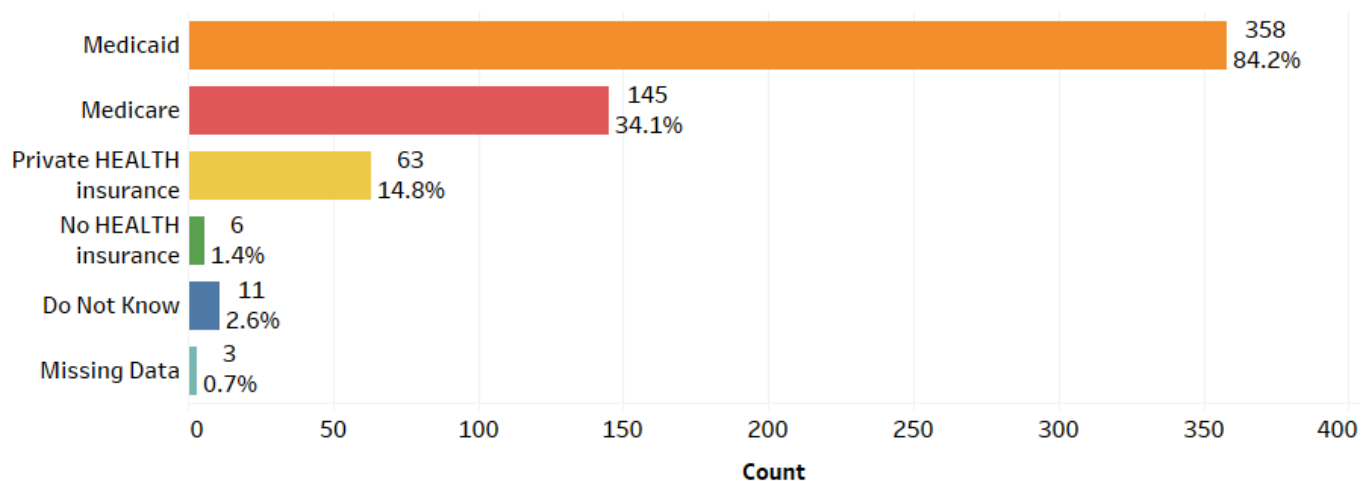
Response	Count	Percentage
I live with family member(s) or guardian(s)	278	65.4%
I live in a group home	75	17.6%
I live in an assisted living facility	31	7.3%
I live by myself	20	4.7%
Other	13	3.1%
I live in a nursing facility	4	0.9%
Missing Data	4	0.9%

#### a) Please fill in this section when "Other" is selected. (N=13)

**Result:** The qualitative responses to this question included living with a spouse, in sponsor homes, host homes, foster care, with a roommate, with a living assistant, and in an apartment beside mom and dad.

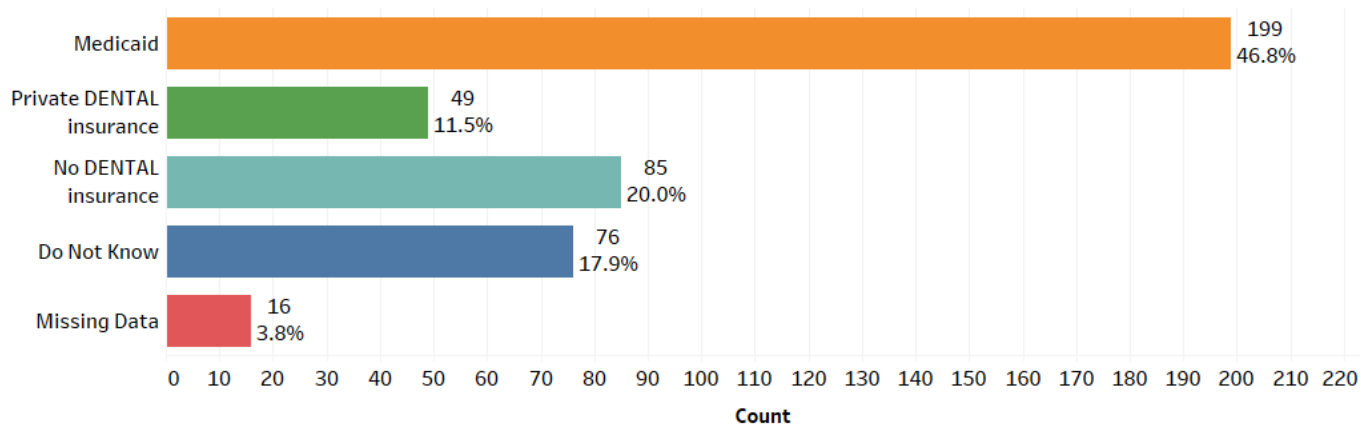
5. Do you have any of the following HEALTH insurances? Check all that apply.

**Result:** For this question, respondents were able to select more than one choice. The overwhelming majority, 84.2%, selected Medicaid and 34.1% selected Medicare. The majority of ISHCN surveyed rely on government support to manage their conditions.



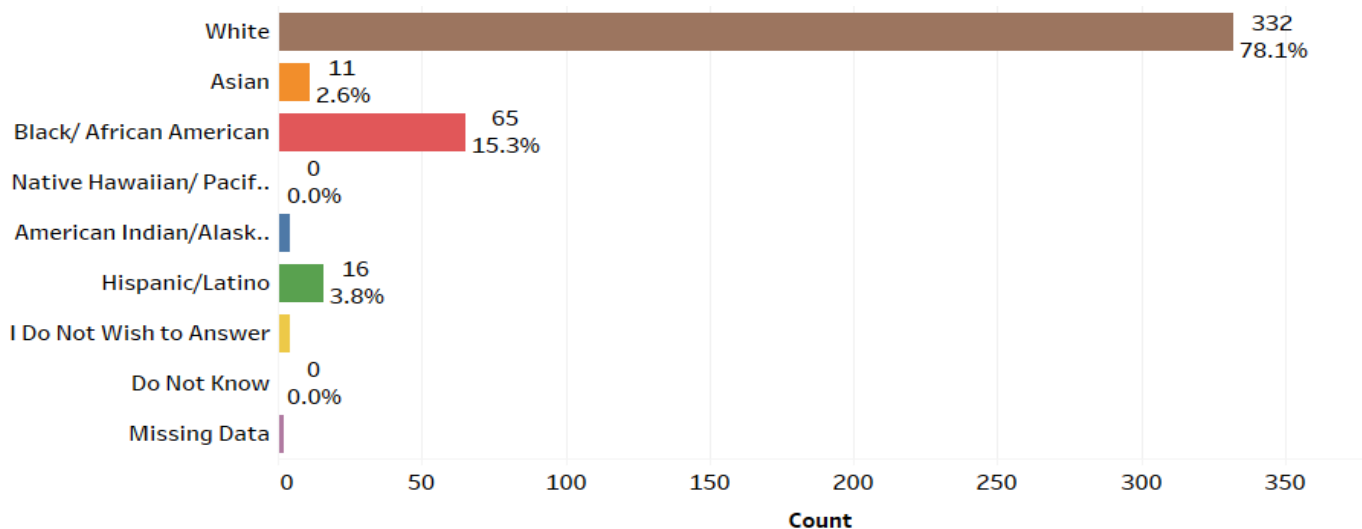
6. Do you have any of the following DENTAL insurances?

**Result:** The majority of participants, 46.8%, reported Medicaid as their primary form of dental insurance as compared to 11.5% with private insurance. While 20% reported having no dental insurance at all. Similar to health care, many ISHCN in this survey rely on government programs to address professional oral health care.



7. Of the following, which describes your race/ethnicity? Choose all that apply.

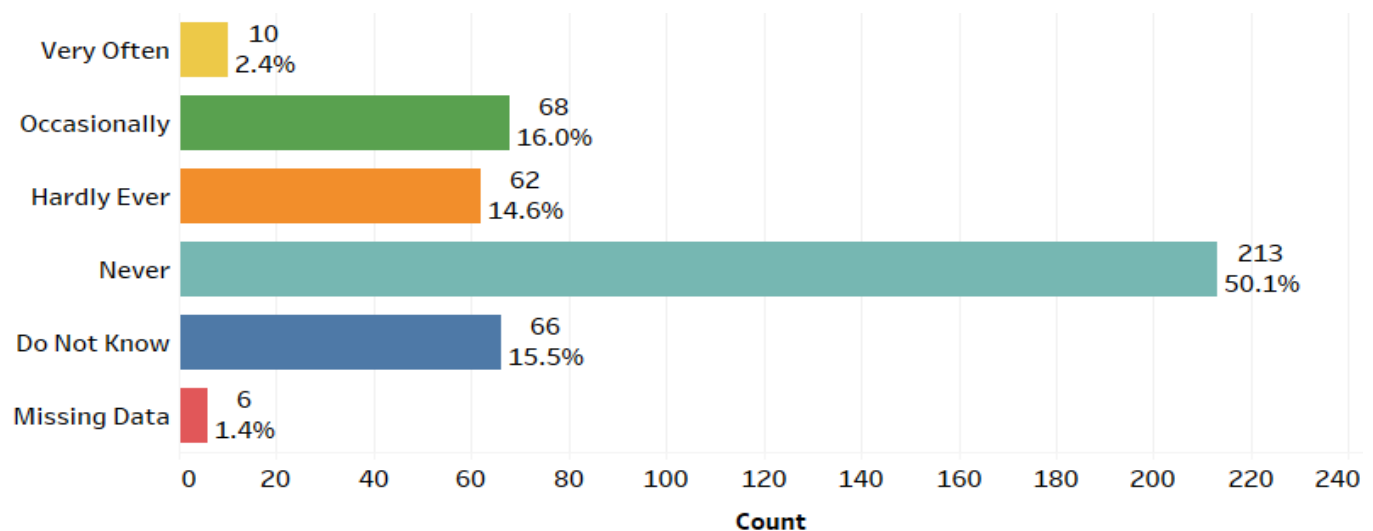
**Result:** The majority of participants self-identified as White (78.1%.) The second most reported race was Black at 15.3%, followed by 3.8% Hispanic/Latino, and 2.6% Asian.



8. During the past 12 months, how often have you had painful aching anywhere in your mouth?

**Result:** Half of the respondents reported never having a painful aching in their mouth in the past year. However, 16% of participants reported occasionally having a painful experience and 14.6% hardly ever experiencing one. Also of note, 15.5% of participants reported not knowing if they had painful aching in the mouth or not. Due to the survey population of ISHCN and/or their caregivers, various levels of intellectual capabilities may influence the responses and ways individuals may identify, report, or experience pain.

Pain reported during the last 12 months:



9. During the past 12 months, have you gone to an emergency room for a mouth-related problem or pain?

**Result:** 96.5% of the sample population reported “No” to having gone to the emergency room for a mouth-related problem in the past year. This may indicate oral health emergencies are not common for ISHCN surveyed or not sufficiently addressed.

Response	Count	Percentage
Yes	3	0.7%
No	410	96.5%
Do Not Know	11	2.6%
Missing Data	1	0.2%

**10. Do you have a problem with your teeth or gums now?**

**Result:** The majority of individuals, 68%, reported not experiencing any teeth or gum issues at the time of the survey. Although, almost 23% of participants reported they were experiencing teeth/gum related problems. This is still a significant percentage of dental need in the surveyed population.

Response	Count	Percentage
Yes	97	22.9%
No	290	68.4%
Do Not Know	35	8.3%
Missing Data	2	0.5%

**11. Do you have a dentist to go to regularly?**

**Result:** Nearly 60% of respondents reported having a dentist to go to regularly, while 36.1% reported not having a dentist. This particular question may show the majority of ISHCN do receive routine dental care by a professional. Over one-third of ISHCN surveyed may not have regular visits to the dentist, which may lead to an increased risk of oral health problems. Please note, however, that the question may not have captured the intended data: While respondents may “have a dentist to go to”, they may or may not actually *visit* that dentist regularly. Therefore, the number of ISHCN that actually regularly go to the dentist may be lower than this data indicates.

Response	Count	Percentage
Yes	254	59.9%
No	153	36.1%
Do Not Know	13	3.1%
Missing Data	4	0.9%

**12. Have you had your teeth cleaned by a dentist or dental hygienist within the past 12 months?**

**Result:** This is in line with the previous question regarding visiting a dentist or hygienist. Again, nearly 60% of participants reported having their teeth cleaned within the past 12 months, compared to 36.2% who have not. This shows a significant percentage of ISHCN without

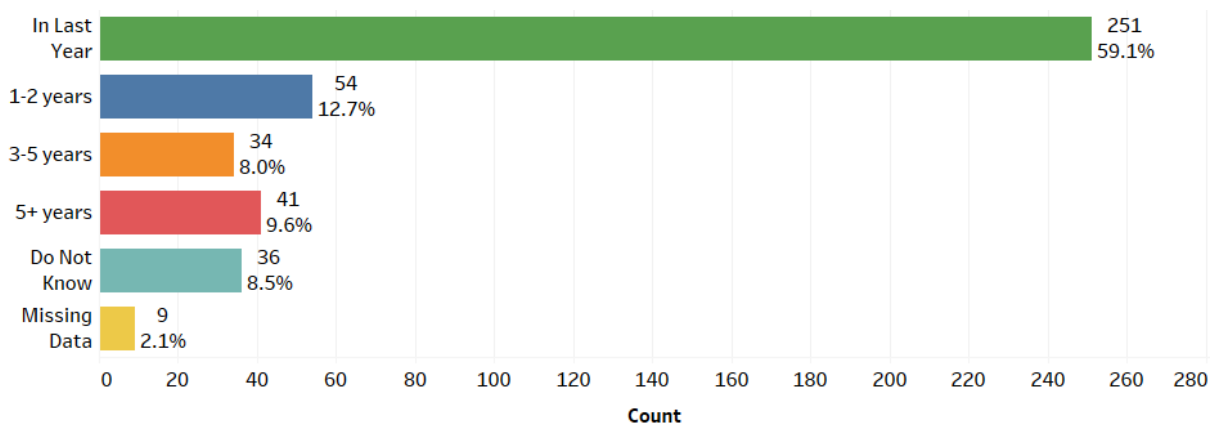


regular access to professional preventive oral care, putting them at risk of developing oral health related problems.

Response	Count	Percentage
Yes	250	59.1%
No	153	36.2%
Do Not Know	14	3.3%
Missing Data	6	1.4%

**13.** How long has it been since you last visited a dentist (include all types of dental providers, free clinics, etc.)?

**Result:** Nearly 60% of respondents reported visiting a dentist or clinic within the past year. This supports the observed trend of the majority of these ISHCN receiving regular dental care. About 21% of the respondents had visited the dentist or clinic between 1-5 years; and about 10% visited a dentist or clinic more than five years ago. Yearly dental visits are vital in maintaining oral health. Overall, about 40% of this ISHCN population did not receive yearly dental care.



**14.** Do you think it is important to care for your teeth and gums?

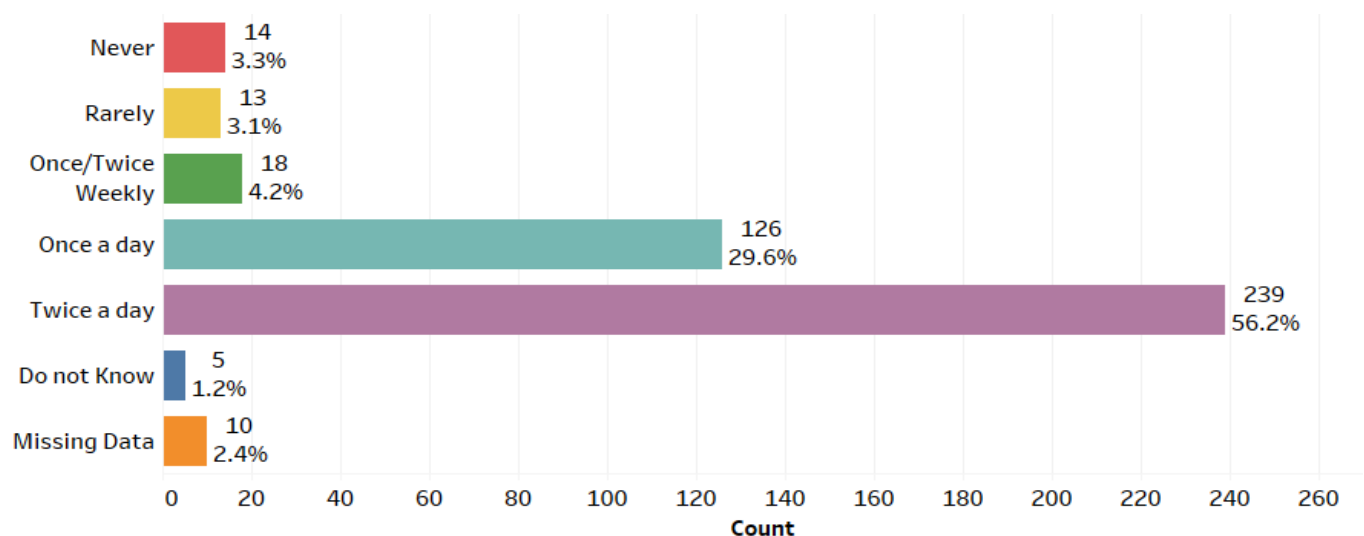
**Result:** 96.5% of participants in this survey reported it is important to care for their teeth and gums. This high percentage may be due to this question being one of the most basic oral health questions and is common knowledge. This question and the next one (#15) are also “leading” questions. Largely, ISHCN and the general population often want to please health care providers or avoid judgment for not caring about their teeth. Which leads to the question: Are they telling us what they think we want to hear? However, it may simply be encouraging to find the majority of ISHCN have a general understanding of their oral health.



Response	Count	Percentage
Yes	408	96.5%
No	1	0.2%
Do Not Know	9	2.1%
Missing Data	5	1.2%

#### 15. How often do you or someone else brush your teeth?

**Result:** Overall, approximately 86% of the ISHCN surveyed knew the importance of at least daily brushing. The majority of individuals, 56.2%, reported brushing their teeth twice daily. 29.6% reported brushing once a day. Even though the concept seems common knowledge, are they only telling us what we want to hear?



#### 16. How confident do you or your caregiver feel about caring for your teeth at home?

**Result:** The majority of participants, 61.8%, reported being very confident in caring for their teeth. About 24% reported being somewhat confident and almost 6% reported being less than confident.

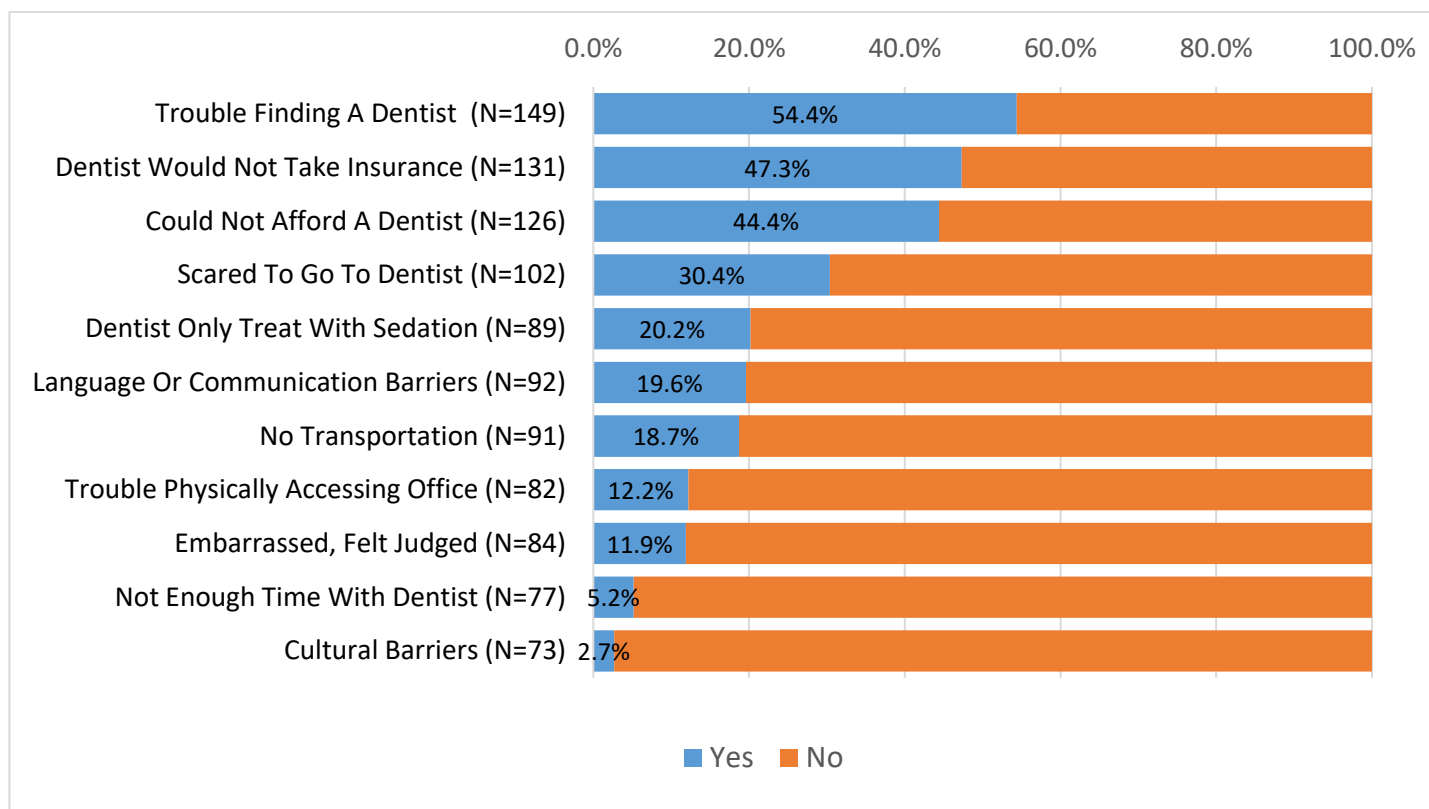
Confidence caring for teeth at home:

Response	Count	Percentage
Very confident	262	61.8%
Somewhat confident	100	23.6%
Less than confident	25	5.9%
Do Not Know	19	4.5%
Missing Data	18	4.2%

17. During the past 12 months, did any of the following things prevent you from receiving dental care? Choose all that apply.

**Note:** This question should have had a preceding question asking if the ISHCN had any barriers or difficulty accessing professional dental care. If they said yes, then they would proceed to this question. As a result, we are basing evaluation of these responses on the number of people who answered the question and NOT the number of people surveyed.

**Result:** Based on the caveat above, 54.4% of the respondents for this question reported have trouble finding a local dentist; 30.4% reported fear of going to the dentist; and 20.2% reported the dentists would only treat them with sedation. Other barriers dealt with the cost of dental care: 44.4% reported not being able to afford a dentist and 47.3% reported the dentist did not accept their insurance. In the graph below, the columns in blue show percentage of ISHCN who reported these specific barriers. N = number of responses for each question.



**Other, please write in (N=42):**

- Over 18 no longer seen
- Has dentures
- Did not feel the need to
- I do not know
- Has ADHD & would not sit still

- Didn't have time
- I would gladly take him to the dentist if they would sedate other than IV
- He has so many issues that have to be addressed & he never has problems when he went. I just didn't have time to deal with it
- I have no teeth
- Has to be medicated
- Need orthodontics
- Does not know how to move his tongue out of the way
- Spent a lot of time in state hospital in past years
- Got sick so had to keep rescheduling
- For medically necessary pulling of wisdom teeth-local dentist had barriers for Medicaid patients
- Dentist didn't understand his disability
- Cost is prohibitive, hard to find a dentist with patience
- Dentist refuses to due to missed appointments
- Will not let us brush her teeth

### **Other data points from the BSS Instrument (see Appendix A):**

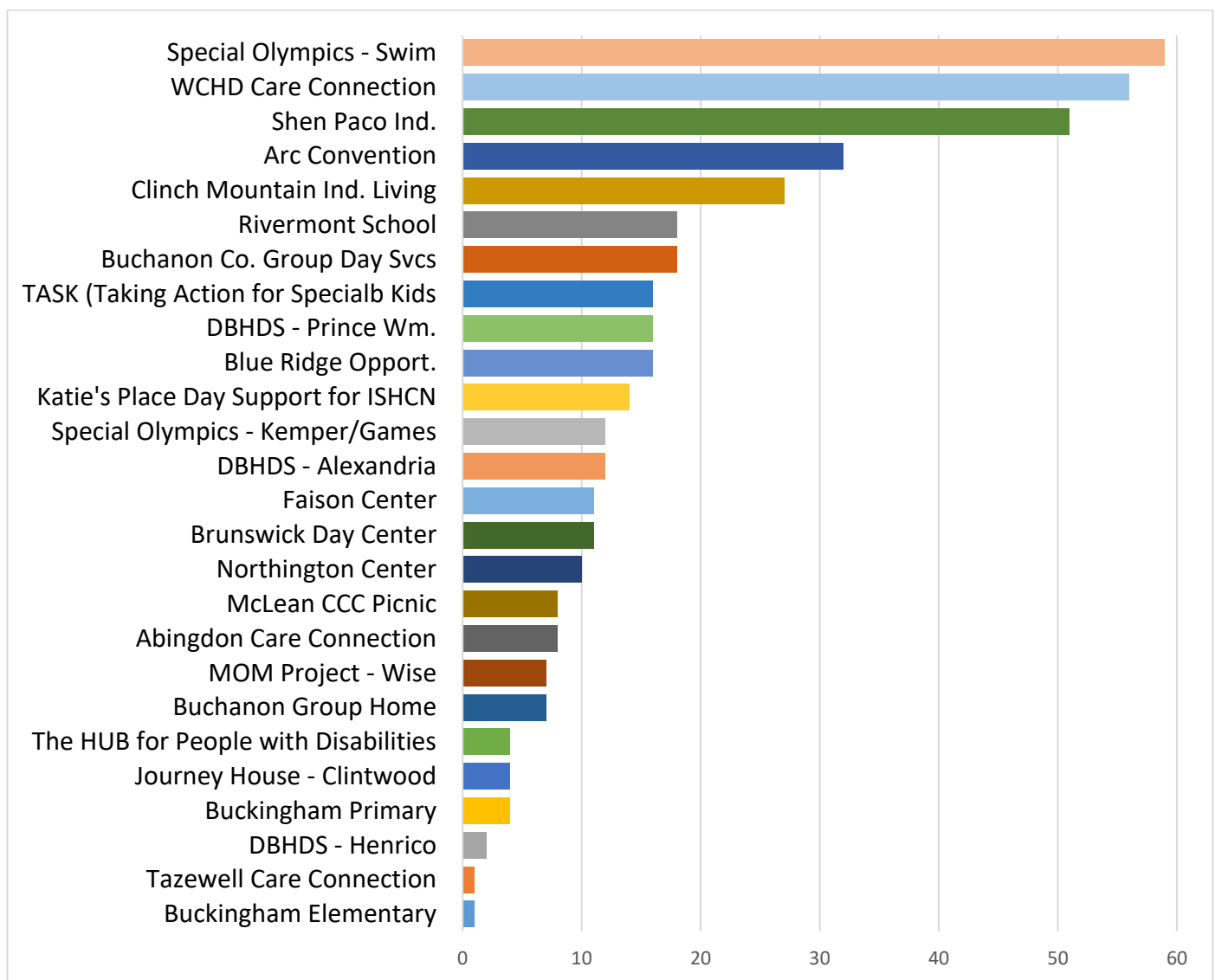
#### **Field Sites**

One instructor at the Virginia Department of Health calibrated all remote-supervised dental hygienist examiners in this study. ISHCN residing in 157 unique localities across Virginia, and were surveyed in 26 unique field sites. Three sites yielded 166 participants – the Special Olympics Swim competition, Washington County Health Department Care Connection for Children, and Shenandoah Shen Paco Industries, which provides an array of services to ISHCN: education, development, vocational training, employment and residential services.

#### **VDH Health Districts**

The majority of surveys came from populations within four health districts: Cumberland Plateau in the Southwest corner of Virginia, Richmond in Central Virginia, Lord Fairfax in Northwest Virginia, and Southside in the southern part of the state.





**Oral Screening Results and Examiner Basics:** Examiners utilized a light source and sometimes a mouth mirror to evaluate the teeth and soft tissues. No x-rays were used to detect tooth decay between teeth, tooth development, or other factors.

**Untreated Decay:** The examiner noted a tooth as untreated tooth decay when breakdown of the enamel or root surface was readily observed. Stained teeth, broken teeth, and broken fillings without the presence of tooth decay were not counted as untreated tooth decay.

**Result:** The oral screening for untreated decay found 26.4% of individuals with obvious decay and 63% with no obvious decay; 10.6% were edentulous.

Response	Count	Percentage
No obvious decay	267	63.0%
Untreated decay	112	26.4%
Edentulous	45	10.6%

**Treated Decay:** Treated decay includes amalgam (silver), composite (white), temporary fillings, crowns, or teeth extracted because of decay. Examiners do not count crowns placed due to trauma. Only missing teeth extracted due to tooth decay are included.

**Result:** The oral screening for treated decay found 51.2% of individuals with previous dental treatment for decay; 38.7% with no previous treatment found; 10.1% were edentulous.

Response	Count	Percentage
None	164	38.7%
Treated Decay	217	51.2%
Edentulous	43	10.1%

**Periodontal “Gum” Disease:** Severe gingivitis is present when there is significant bleeding, swollen gums, and oral debris.

**Result:** The oral screening for signs of periodontal disease found 27.1% of individuals with severe gingivitis; 63.1% with no obvious need for periodontal care until routine visit; and 9.9% edentulous.

Response	Count	Percentage
No need for periodontal care until routine visit	268	63.1%
Severe Gingivitis	115	27.1%
Edentulous	42	9.9%

**Missing Teeth:** Only missing teeth due to tooth decay or periodontal disease are included. The examiner did not count missing teeth due to orthodontic extractions, accidents, or self-injurious behavior as lost due to disease.

**Result:** The oral screening for missing teeth found almost 37% of individuals with teeth missing due to decay or periodontal disease and 63.1% with no teeth lost due to disease.

Response	Count	Percentage
No teeth missing due to decay or periodontal disease	267	63.1%
Teeth missing due to decay	156	36.9%

**Suspicious Soft Tissue Lesions:** Suspect lesions include any soft tissue color or texture changes, swellings, and/or other abnormalities.

**Result:** The oral screening for suspicious soft tissue lesions found only 7.1% of individuals had suspect lesions present as compared to about 93% with no lesions found.

Response	Count	Percentage
No suspicious soft tissue lesions	395	92.9%
Suspicious lesions present	30	7.1%

**Urgent Care Needed:** Early dental care means the individual needs to see a dentist within the next several weeks because of untreated decay, broken restorations, mobile teeth, or periodontal disease, but they do not have pain or an infection. Urgent dental care means the person needs dental care within 24 to 48 hours because of signs or symptoms that include pain, infection, swelling, or tissue changes suspected to be a significant disease, like carcinoma. Advanced periodontal needs includes severe inflammation or substantial oral debris requiring more urgent treatment needs.

**Result:** The oral screening for urgent care needed found 30.5% of individuals needing early dental care, 4.3% needing care within 24-48 hours, and 65% had no obvious dental problem.

Response	Count	Percentage
No obvious dental problem	276	65.2%
Early care needed	129	30.5%
Needs dental care within 24-48 hrs.	18	4.3%

### **Examiners' Quotes: What Worked Well?**

- Overall, I think everything went well. The staff and participants were happy we were there! We very much enjoyed being able to work with the ISHCN participants.
- Almost all of our participants did excellent with our screenings and loved the goody bags that we gave them. They were happy to see us and did their best to understand all our dental education.
- Having fun with the patients was the best part. I did not always immediately sit them down and do an exam. Many times, I would play with individuals and get them comfortable before I would do the exam. This allowed them to calm down and participate better. Seeing these individuals happy was also very rewarding.
- The staff members helped get the participants because it was extremely difficult to read handwriting of the caregivers or the participants on the forms. The staff members would bring the participants to our location and walk them back.
- The participants loved the goody bags. We did dental education at one site for all their clients and all three sites welcomed us back for a dental education day.
- We found doing the screenings in a private room worked great, less noise and confusion for the participants.

### **Examiners' Quotes: Lessons Learned and Advice for Future Visits:**

- At least six months prior to the BSS is preferable to gain participation with more facilities, residential homes, events, etc.
- For ISHCN unable to fill out their own questionnaire: Caregivers/Parents attending with their individual could provide the history part about dental care. However, chaperones, facility staff, and coaches did not always feel comfortable answering all questions because they did not know the individual well enough. In addition, getting consent for the screening could be a challenge if the person with them did not have the authority.
- Next time I would send out the paperwork before my scheduled appointments to get proper documentation before the appointment, so that guardians can sign and more individuals can participate.
- Some were non-verbal so it was difficult to communicate if we had any questions to ask them and their caregivers were not always there to answer those questions. Some did not want to sit down for our screenings and some were upset at our screenings because they were scared.
- The challenge was not locating sites, but getting them onboard to participate in such a short timeframe. Some sites agreed to the survey, but August was not a good time, or we did not contact them with enough time to say yes and participate.
- Many of the individuals I saw needed help finding a dental home. There are just not that many providers out there willing to work with this population.
- The biggest challenges faced were individuals with severe intellectual and developmental disabilities. These individuals need such specialized care it was difficult doing a proper exam. Some individuals would not participate due to behavior.



## **Future Plans**

This final report is available to all collaborative partners, participating venues/sites, ASTDD, CDC, HRSA, and other grant funding sources.

With the successful first ISHCN BSS in VA completed, the plan is to continue to administer this survey every five years.

## **Conclusion**

Despite limited comprehensive open-mouth basic screening data at the state and federal level, ISHCN, parents/caregivers, medical/dental professionals, and other interested parties agree there are definite barriers to good oral health for many ISHCN.

It is our hope that sharing the results of this survey will promote actionable solutions and funding.



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**Appendix A: ISHCN BSS Cover Letter  
and Survey Instrument – 3 pages**



## **COMMONWEALTH of VIRGINIA**

*Department of Health*

M. Norman Oliver, MD, MA  
State Health Commissioner

PO BOX 2448  
RICHMOND, VA 23218

TTY 7-1-1 OR  
1-800-828-1120

June 1, 2019

Dear Participant/Parent/Caregiver/Authorized Representative:

You (or an individual within your care) has been selected to take part in a state health department survey and free screening to learn about the oral health of individuals who have special healthcare needs across Virginia. The purpose of this survey is to gather information to assist the Virginia Department of Health and its partners in developing and improving programs that will benefit individuals who have special healthcare needs in your area and the entire state, and document progress made with current programs. **All participating individuals will receive free oral health supplies.**

After the questionnaire is complete, a licensed dentist or dental hygienist will look at the participant's teeth and gums with a mirror. This screening takes approximately five minutes. **It does not take the place of a regular dental check-up with a dentist who is able to take x-rays and provide a comprehensive examination and treatment plan.** All personal information you provide is confidential and will not be shared with anyone.

While this survey is voluntary, we encourage you to participate as a means of helping plan for the future health of all individuals who have special healthcare needs in Virginia. It is important for the participant to participate even if he/she has had a recent dental check-up. To participate, please complete the attached questionnaire, sign the permission form, and return it to a screener.

If you have any questions about the screening, the dental professional at your site can answer them. You may also contact Kami A. Piscitelli with the Dental Health Program at [kami.piscitelli@vdh.virginia.gov](mailto:kami.piscitelli@vdh.virginia.gov) or 804-864-7804.

**Thank you for participating!**

Sincerely,

Kami A. Piscitelli, BSDH, RDH  
Virginia Department of Health, Dental Health Program



## 2019 ISHCN Dental Questionnaire

*Individuals with special health care needs (ISHCN) have medical, physical, sensory, intellectual, or psychological conditions making it necessary to modify participation in home, work, or social activities. This can include intellectual or developmental disorders, long-term chronic health conditions, and physical limitations. ISHCN often need caregiver or healthcare support, assistance, or special services.*

Place a check or an X in the boxes that apply. ☒

1. **Do you have a special health care need, condition, disability, or chronic illness?**  
(See the definition of a special health care need used for this survey)  
☐ Yes      ☐ No      ☐ Do Not Know  
If yes, please indicate the condition here: \_\_\_\_\_
2. **Your age in years** \_\_\_\_\_
3. **Your city or county of residence** \_\_\_\_\_
4. **Which of the following best describes your living situation?**  
☐ I live with family member(s) or guardian(s)      ☐ I live in a group home  
☐ I live in an assisted living facility      ☐ I live by myself  
☐ I live in a nursing facility      ☐ Other: \_\_\_\_\_
5. **Do you have any of the following HEALTH insurances?** Check all that apply.  
☐ Medicaid    ☐ Medicare    ☐ Private health insurance    ☐ No health insurance    ☐ Do Not Know
6. **Do you have any of the following DENTAL insurances?**  
☐ Medicaid    ☐ Private dental insurance    ☐ No dental insurance    ☐ Do Not Know
7. **Of the following, which describes your race/ethnicity? Choose all that apply.**  
☐ White      ☐ American Indian/Alaska Native  
☐ Asian      ☐ Hispanic/Latino  
☐ Black/African American      ☐ I do not wish to answer  
☐ Native Hawaiian/ Pacific Islander      ☐ Do Not Know
8. **During the past 12 months, how often have you had painful aching anywhere in your mouth?**  
☐ Very often    ☐ Occasionally    ☐ Hardly ever    ☐ Never    ☐ Do Not Know
9. **During the past 12 months, have you gone to an emergency room for a mouth-related problem or pain?**  
☐ Yes      ☐ No      ☐ Do Not Know
10. **Do you have a problem with your teeth or gums now?**  
☐ Yes      ☐ No      ☐ Do Not Know
11. **Do you have a dentist to go to regularly?**  
☐ Yes      ☐ No      ☐ Do Not Know
12. **Have you had your teeth cleaned by a dentist or dental hygienist in the past 12 months?**  
☐ Yes      ☐ No      ☐ Do Not Know
13. **How long has it been since you last visited a dentist (include all types of dental providers, free clinics, etc.)?**  
☐ In last year    ☐ 1-2 years    ☐ 3-5 years    ☐ 5+ years    ☐ Do Not Know



14. Do you think it is important to care for your teeth and gums?  
☐ Yes      ☐ No      ☐ Do Not Know
15. How often do you or someone else brush your teeth?  
☐ Never      ☐ Rarely      ☐ Once/twice weekly      ☐ One a day      ☐ Twice a day      ☐ Do Not Know
16. How confident do you or your caregiver feel about caring for your teeth at home?  
☐ Very confident      ☐ Somewhat confident      ☐ Less than confident      ☐ Do Not Know
17. During the past 12 months, did any of the following things prevent you from receiving dental care? Choose all that apply.
- |   |  |
|---|--|
| <input type="checkbox"/> Trouble finding a dentist  | <input type="checkbox"/> Dentist would not take my insurance           |
| <input type="checkbox"/> Could not afford to go to the dentist  | <input type="checkbox"/> No transportation for dental appointments     |
| <input type="checkbox"/> Scared to go to the dentist  | <input type="checkbox"/> Embarrassed, felt judged, or lack of respect  |
| <input type="checkbox"/> Cultural barriers  | <input type="checkbox"/> Language or communication barriers            |
| <input type="checkbox"/> Dentist would only treat me with sedation  | <input type="checkbox"/> Not enough time with the dentist or hygienist |
| <input type="checkbox"/> Trouble physically accessing the office <input type="checkbox"/> Other, please write in: _____ |  |
| or dental chair (ramps, doorways, equipment) _____  |  |

Yes, I want to receive a free dental screening.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Yes, I want the individual I represent to receive a free dental screening.

Parent/Caregiver/Authorized Representative

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

(You must be a legal guardian or medical power of attorney to provide consent.)

**Please do not write below this line: FOR EXAMINER USE ONLY**

Screening Date: ____/____/2019	Site Name: _____	Examiner ID# _____
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UNT D	TRE D	PERIO
<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 0
<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 1
<input type="checkbox"/> 9 (E)	<input type="checkbox"/> 9 (E)	<input type="checkbox"/> 9 (E)
MISSING	SUSP. LESION	URG
<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 0
<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 1
		<input type="checkbox"/> 2



**Appendix B: 2019 ISHCN BSS Chart of conditions, disabilities, syndromes, and disorders reported and categories utilized for the ISHCN BSS reporting**

<b>2019 ISHCN BSS Condition Headings and Subheadings</b>				
<b>Chronic Medical Conditions</b>	<b>Developmental Disorders</b>	<b>Genetic Disorders</b>	<b>Intellectual/Cognitive Disabilities</b>	<b>Neurological Disorders</b>
HTN - Hypertension	Down Syndrome (Trisomy 21)	Maple Syrup Urine disorder	Intellectual disability (bad old term: retarded/MR)	Seizure disorder - SD
Diabetes	DD - Developmental Disorder	Batten Disease (rare brain disease)	ID - Intellectual disability	Epilepsy
GERD - Gastric Reflux Disease	IDD - Intellectual/Developmental Disorder	CHARGE syndrome	Degeneration of brain/cerebellum	Autism Spectrum disorder - ASD
Heart Disease	Delayed development	Fragile X syndrome	IDD - Intellectual/Developmental disorder	Asperger's syndrome
Morbidly Obese	Microcephaly	Dyslexia	Cognitive disability	Lennox-Gastaut syndrome
Bowel dysfunction/issues	Fetal Alcohol Effects - FAE	22Q Deletion syndrome - DiGeorge syndrome	Mental disability	Tourette's syndrome
Asthma	Fetal Alcohol Syndrome - FAS	Tuberous sclerosis complex - TSC		Brain damage
Hypermyalgia	Lissencephaly	Connective tissue disorder		Learning disability
Thyroid Disease	Gene duplication	XLH - X-linked hypophosphatemia (kidneys)		Speech impairment
Migraines	Chiari malformation	Lupus		Gray matter heterotopia
Vitamin D Deficiency	Hand anomalies	Chromosomal disorder		Multiple Sclerosis
Kidney Disease	Cleft lip/palate	Neurofibromatosis		
Pancreatic illness/disease	Poland syndrome	Wolf-Hirschhorn syndrome		
Connective tissue disorder	Spina bifida	Dandy-Walker syndrome		
Alopecia		Osteogenesis Imperfecta		
Black lung disease		Nemaline Myopathy		
IDF 72 (combat wounded)		Charcot-Marie-Tooth disease (CMT)		
Hypothyroidism		Wilms' Tumor		
Cerebral vascular accident - Stroke		Congenital Hydrocephalus		
Myopathy				
Acquired Hydrocephalus				
<b>Physical Disabilities</b>	<b>Psychological Conditions</b>	<b>Sensory Disabilities</b>	<b>Suspected Disability/Condition</b>	
Polio	ADD/ADHD - Attention Deficit disorder	SID - Sensory Integration disorder	Suspected Intellectual disability	
Club Foot	Depression/Depressive disorder	Sensory Processing disorder		
Scoliosis	Anxiety Disorder/Generalized Anxiety			
CP - Cerebral Palsy	OCD - Obsessive Compulsive disorder			
Blind	Bipolar disorder			
Lumbar Stenosis	Panic disorder			
Wheelchair use	Mental disorder/illness			
Glaucoma	Affective Schizoid disorder			
Hypertonia	PTSD - Post Traumatic Stress disorder			
Usher syndrome	Schizophrenia			
Deafness	Dementia		<b>D/O - abbreviation for disorder</b>	
Hearing impaired	Disruptive Impulse Control			
	Conduct disorder			
	MDD - Major Depressive disorder			
	Personality or Borderline Personality disorder			
	Recurrent episode or brief depression - RBD			
	ODD - Oppositional defiant disorder			